NO RHYME OR REASON

We have read and heard a lot about the disparities in the cost of care from one hospital or clinic to another. We have read and heard a lot of grumbling about the uneven availability of health care services in this country. Many of us have been outraged to learn that Pharma companies can charge whatever they want for drugs that they have developed because our elected representatives passed legislation that provides Pharma with this discretionary power.

These same laws allow Pharma to provide a percentage of the direct cost of the medications to doctors. Although a mandate in the Affordable Care Act requires information on Pharma payments to physicians be made public via the CMS Open Payments online database, this is little consolation to thousands of patients who bear the brunt of this inequality in our payment system.

Because our system is so dysfunctional and our cost of care so elevated, there are daily instances of patients declaring bankruptcy because they cannot afford their prescription drug costs. There are also too many situations where patients are dying prematurely because they simply cannot afford to obtain the medications that could restore their health.

In America, the average health expenditure per individual patient is approximately \$8,200 per year. That is at least one and a half times the amount per patient compared to other developed countries across the world. Among a broad range of hospital services (both medical and surgical), the average price in the United States is 85 percent higher than the average in many countries, including: Canada, the Netherlands, Japan and the relatively affluent European countries such as France, Sweden and the United Kingdom.

More outrageous is that our outcomes compared to these countries are far worse. The Commonwealth Fund in a report in 2014 entitled "Mirror, Mirror on the Wall" that the United States health care system is the most expensive in the world, but consistently ranks dead last. The Countries compared included in order of ranking:United Kingdom, Switzerland, Sweden, Australia. Germany & Netherlands (tied), New

Zealand & Norway (tied) France, Canada, United States, last. This assessment included prior surveys and national health system scorecards as well as data from the World Health Organization (WHO) and the Organization for Economic Cooperation and Development (OECD). The report was based on rankings on key indicators including:

- 1. Quality: effective care, safe care, coordinated care, and patientcentered care.
- 2. Access: The most notable way the U.S. differs from other industrialized countries is the absence of universal health insurance coverage. Other nations ensure the accessibility of care through universal health systems and through better ties between patients and the physician practices that serve as their medical homes.
- 3. Efficiency: The U.S. has poor performance on measures of national health expenditures and administrative costs as well as on measures of administrative hassles, avoidable emergency room use, and duplicative medical testing.
- 4. Equity: The U.S. ranks a clear last on measures of equity. Americans with below-average incomes were much more likely than their counterparts in other countries to report not visiting a physician when sick; not getting a recommended test, treatment, or follow-up care; or not filling a prescription or skipping doses when needed because of costs.
- 5. Healthy lives: The U.S. ranks last overall on all three indicators of healthy lives mortality amenable to medical care, infant mortality, and healthy life expectancy at age
- In 2012, The Institute of Medicine issued another of their sentinel reports: Best Care at Lower Cost, consisting of several key recommendations including recommendations on our infrastructure, our ability to deliver patient-centered evidenced-based clinical care, our paying closer attention to population health, payment structures that reward best care as the lowest possible cost, equity on cost and outcomes of care, and a culture of care that supports and encourages best practices and continuous improvement.

There is not very much in our current health care system that meets any of these goals.

One bizarre example in our system of policies that have "No Rhyme or Reason" is the way in which durable medical equipment, (DME) is handled. DME includes such devices as: iron lungs, respirators, intermittent positive pressure breathing machines, medical regulators, oxygen tents, crutches, canes, trapeze bars, walkers, inhalers, nebulizers, commodes, suction machines, and traction equipment purchased by a payer and kept in the patient's home. Although payers usually cover the cost of DME hardware, they often refuse coverage of the medication required to make the device functional. I recently ran into this problem when I developed severe bronchial asthma, pulled out my nebulizer that Medicare had paid for, was refused coverage on the medication I needed. Although my physician wrote the necessary prescription, the pharmacy informed me that I needed prior approval from my payer. After several hours, I learned from the pharmacist that the cost of the medication out-ofpocket was \$20 which I quickly paid. Not all medications are that inexpensive, nor can all patients afford to make the payment. If you cannot get the medication to operate the device, it is useless. My niece, who has Type I diabetes, had a similar experience with even more serious consequences. The payer of her health insurance agreed to pay \$8,000 for a new pump, sensor and specific glucometer that work together to regulate her insulin. However they have consistently refused to pay for the specific test strips that work with the glucometer and are needed to check her sugars and determine how much insulin to direct the pump to give her. Test strips are not a simple \$20 bill. Over time they cost hundreds of dollars and have to be used several times a day.

To add to the inequity, customized durable medical equipment and medications are paid at rates that are determined item by item, by the regional carrier, based on competitive bidding. Thus, the pricing of such devices differ by region or location with no standards for how the prices are determined This type of the disparity also carries over to the

pricing of procedures and treatments such as MRIs, colonoscopies, etc. from one medical clinic to another, even, within the same geography.

Although no one wants to see the US move to a national health system, (which most developed nations in the world have), we need to figure out a way to monitor pharma and payers so that price gouging patients, payments to doctors and the disconnect about what is covered and what is not covered becomes more transparent, logical and equitable. We cannot continue on this path. It is undemocratic, unfair, unethical, and makes a sham of our national obligation to help all patients receive basic health services.

The only way that is going to happen in our democratic society is to legislate for a quasi-public authority that has oversight of healthcare payment on a Federal level, and works with each state to institute uniformity into the cost of care. With an infrastructure that can oversee what is going on we might begin to realize lower costs and greater equity in our health system.

THE ROLE OF DIGNITY IN HEALTH CARE

Every patient wants to be treated with dignity. However, when you are sitting in a doctor's exam room, holding together a hospital gown that somehow does not want to completely fit around you, or close properly, it is difficult to feel that you have any dignity. When the doctor comes into the room and barely listens to you or looks at you, while he or she is checking your health record on the computer, it also feels as though you do not have much dignity. When the doctor explains the treatment options for your problem and does not take the time to listen to you analyze your issues, a culture of dignity is missing from this interaction.

Donna Hicks, PhD, an associate at the Weatherhead Center for International Affairs at Harvard University, has worked for over a decade in the field of international conflict resolution and has published a sentinel book called Dignity, its Essential Role in Resolving Conflict. Although the book is focused on a culture of dignity in the workplace, there are many parallels that are essential to health care organizations and health care professionals who strive to offer quality care.

The ten elements of dignity that Dr. Hicks outlines in her book, so relevant in a health care setting include:

- 1. Acceptance of every person's individuality and identity.
- 2. Inclusion making people feel they belong.
- 3. Safety putting people at ease.
- 4. Acknowledgment -giving people full attention by listening, hearing, validating and responding to their concerns, feelings and experiences.
- 5. Recognition validating others for their personal traits and talents.
- 6. Fairness Treating people equally.
- 7. Benefit of the doubt trusting people.
- 8. Understanding believing what others think matters.
- 9. Independence Encouraging people to act on their own behalf empowerment.
- 10. Accountability taking responsibility for actions.

There are a plethora of patient stories where doctors ignore the patient's point of view or explanation of what is wrong. There are frequent instances when doctors in the exam room fail to communicate with their patients or even look them in the eye. There are countless times when intentionally or unintentionally healthcare professionals strip away a patient's sense of dignity by patronizing them.

<u>Duncan Cross</u>, a patient who has suffered with Crohns disease for a number of years wrote a blog post that describes his first-time encounter with a gastroenterologist. He talks about this physician's attitude and equates it to the attitude of folks who ran segregated lunch counters many years ago, attitudes that are no longer acceptable. He discusses this physician's refusal to take him seriously when he described the pain he was suffering, because certain markers were not present to indicate that pain. He appeals to the physician, in a letter, to view patients as equal partners in their

care, something that this physician clearly did not do. What Duncan advocates is the essence of what it means for healthcare professionals – doctors, nurses, nurse practitioners, therapists and physician assistants to treat patients with dignity.

So how do physicians and hospitals consciously create a culture incorporates the ten elements of dignity?

At Mount Auburn Hospital, in Cambridge, MA, the Dignity Matters campaign was launched last year to instill in everyone from the Executive Suite to the Environmental Services department how important it is to recognize the practice of treating everyone, including patients, with dignity. Initiated by the Past President of the Medical Staff, Dr. Anne d'Avenas, the program was launched with a series of workshops where hospital, professional and administrative staff participated in a presentations/discussions, followed by breakout sessions which focused on various scenarios that illustrate lessons learned about treating colleagues, patients, family and visitors with dignity. Using buttons, posters and flyers, the Dignity Matters campaign is visible throughout all of Mount Auburn's affiliated offices. There is a plan to incorporate Dignity Matters into the Mount Auburn web site.

In today's stressful world it is difficult to maintain a culture of compassion and respect throughout the health care system. It is even more challenging to improve the patient experience and increase satisfaction by insuring that we are all treated with the dignity each of us is automatically entitled to.